

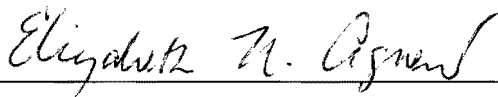
**How Doing Good Works in America: A Case Study of the National Multiple  
Sclerosis Society**

An Honors Thesis (HONRS 499)

by

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## **Abstract and Acknowledgements**

### **Abstract**

This project was written in order to discuss some of the moral issues that arise when individuals desire to give time and money to a philanthropic cause. I began studying these issues in an undergraduate class titled, “Love and Justice: Moral Issues in Doing Good,” taught by the advisor to this project, Dr. Elizabeth Agnew, in the Department of Philosophy and Religious Studies. Drawing heavily on Patricia Werhane’s article titled, “Focused Fairness in Philanthropy,” I discuss how individuals can make educated decisions when donating their time and money so that the most “good” can be achieved. I also discuss how a large philanthropic organization like the National Multiple Sclerosis Society can address these issues as well, in order to ensure their donors that the Society is a worthy recipient.

I chose the NMSS as sample philanthropy to explore these issues because of my personal ties to Multiple Sclerosis. My maternal grandmother, after whom I am named, died eleven years before my birth because of complications related to MS. My mother was diagnosed with MS herself twenty-six years ago, after the birth of my older brother. So not only does this project explore the moral issues in “doing good,” but it also explores what Multiple Sclerosis is and how the NMSS came to be.

As a way to do my own good, I set up a Memorial Fund through the NMSS Website to honor my late grandmother and attempt to raise some money for the cause. I sent a letter to family and friends explaining my project and asking them to join me in donating money for a cause they are all affected by, to an organization that was reliable. In addition to the letter, I provided a “Guide to Giving,” which summarizes the findings of this project, explains why the NMSS is a worthy recipient of their donations, and gives examples of questions individuals

could ask themselves when considering where to give in the future. These two documents, the letter and “Guide to Giving,” can be found in the Appendices.

### Acknowledgements

- I want to thank Dr. Elizabeth Agnew for taking the time to advise and direct me on this project. She was essential to the brainstorming process, and in encouraging me during the project’s unfolding.
- I would also like to thank Tiffany Bogard, President of the Indiana chapter of the NMSS. The time she took out of her busy schedule to meet with me made this project richer than I could have ever done on my own.
- Finally, I would like to thank my mother and grandmother simply for giving me life, even when their lives were so challenging.

## **I. Introduction**

This project brings together two very distinct interests of mine: Multiple Sclerosis and “doing good.” My mother was diagnosed with Multiple Sclerosis after the birth of my older brother in 1982, and her mother died from the effects of the disease while still in her early fifties. Multiple Sclerosis, or MS, is an autoimmune disease that causes a person’s immune system to attack the myelin coating found around nerve cells in the Central Nervous System. When the myelin gets attacked and destroyed, the nerves are left without protection and often with scarring that affects their ability to send and receive messages. As a result, MS patients lose much of their mobility and also suffer from severe fatigue; my mom was in a wheelchair full time by the time I was in fourth grade. So MS has impacted my family for a couple of generations, and I am naturally interested to know more about it and join the search for a cure.

The idea of “doing good” is something that has long been influencing my search for a career path. As a college student, and especially as one who will graduate soon, I am constantly being asked, “What are you going to do with your life?” I have been unable to come up with any more specific of an answer than, “I don’t know, but I know I want a job I love going to every day and one that helps people.” When I took Dr. Agnew’s class in the fall of 2006 titled RELST 450 “Love and Justice: Moral Issues in Doing Good,” I learned just how complicated wanting to help people can become. Authors like Robert Gross, David Craig, and Patricia Werhane have added their views to this paper by proposing systems of their own for deciding how to do the most good.

In his essay, “Giving in America: From Charity to Philanthropy” Gross traces his ideas of the difference between “charity” and “philanthropy” through the history of the American people. The Puritans living in the early colonies relied heavily on each other for charitable support when

one of them was in need. Following the divine command to “do unto others as you would have them do unto you,” they gave aid to anyone who came to their doorsteps, as long as they lived within their community (Gross 32). Should an outsider require aid while inside the confines of their community, this person would be hard put to find any aid within the town they didn’t belong to. This style of government kept the towns from having to establish poorhouses or asylums, and followed a very Marxist formula: “from each according to his ability, to each according to his needs” (Gross 33). As the colonies grew, and technology and means of travel improved, this idea of “insider” charity became impractical, and it was in Philadelphia where the idea of philanthropy evolved. As the fourth-largest city in the British Empire, it was moved by “an inclination to promote the Publick (sic) Good” by establishing a set of organizations like the Foundling Hospital in London and the Prison Society in Philadelphia (Gross 37, 43).

So we see the progression of aid in history from charity to philanthropy in the development of the original colonies. Likewise we can see this progression from face-to-face charity, in early cases of MS, to the development of philanthropy using organizations such as the National Multiple Sclerosis Society (or NMSS). Gross provides an excellent framework for the understanding of this development of my project as he concludes his article with the understanding that “organized philanthropy never eliminates the urge to personal service [charity]” (48). His emphasis that *both* charity and philanthropy are important to do the most good makes his contribution a worthy one to this project, and as I trace the history of MS and the NMSS it will be apparent that both charity and philanthropy are important to doing the most good for this cause as well.

It is obvious enough that there are plenty of people who want to make a difference in the lives of others, and they are willing to sacrifice money and time in order to do so. A single

person has several decisions to make when looking for opportunities to help others: what to give, where to give, how much to give, etc. Patricia H. Werhane's essay "Focused Fairness in Philanthropy" offers a guide to evaluating the worthiness of an organization like the NMSS, and shows how one can make an informed decision when considering where and how to give. Werhane discusses her idea of "focused fairness," which she uses as a much needed "principle of fairness to evaluate philanthropic activities, and...distributive criteria for that form of giving" (93). She comes up with four principles to support her idea of focused fairness and several principles of distribution. Meanwhile, in his article "The Give and Take of Philanthropy," David Craig proposes that "people give on the basis of their vision of a good life," and this also provides an important input to the discussion (57).

But how does a nationwide organization like the NMSS make these kinds of personal decisions? With millions of dollars flowing through the organization every year, how are the moral issues resolved by the thousands of chapters throughout the nation? Who is making the hard ethical choices when it comes time to decide where the money should go? How is the NMSS competing for money and manpower in the tidal wave of philanthropies that sweep our nation? In light of what has been presented from philosophers and authors before, these questions and more will be addressed. My interview with Tiffany Bogard, the President of the Indiana chapter of the NMSS will provide her answers to these questions as well.

Using Multiple Sclerosis as a focal example, and the National Multiple Sclerosis Society as a case study of philanthropy, this paper will demonstrate several ways in which to determine how to do the most good. In order to understand what makes these examples valid and revealing, I will first offer a cursory explanation of what MS is, and how it affects those who have it and those who love the people who have it. Then I will reveal how the NMSS came into

being, and how it has grown to the size and influence it is today, drawing heavily on Gross and his findings about philanthropy and history. Finally, I will end by explaining how the NMSS today is attempting to do the most good possible with the resources they have available: how they decide what funding goes where, which needs of their clients are being met and which are not, and what the future of their organization looks like.

## **II. Multiple Sclerosis: A Medical Perspective**

Multiple Sclerosis is commonly agreed to be a chronic, autoimmune disease that attacks the myelin, “the fatty substance that surrounds and protects the nerve fibers in the central nervous system” (About MS, “What is MS?”). When the myelin is lost in a certain area, there is scar tissue left in its place, and this is called sclerosis. The lack of myelin and the presence of sclerosis disable the nerves from sending messages the way they were meant to. This can be better understood if one thinks about the rubber coating surrounding electrical wires leading to a light bulb. Breaks in this rubber casing “interfere with the transmission of electricity” (Rumrill and Hennessy 4). The electricity running through the wires is suddenly unprotected and can escape, making the light bulb shine less brightly and sometimes flicker because of its inconstant source of power.

A person living with MS will experience the same lack of energy and flickering of power. Severe and chronic fatigue is one of the major symptoms associated with this disease. On the one hand, depression, nocturnal muscle spasms, and the considerable amount of effort it takes some MS patients to complete even the simplest of tasks can all cause a level of general fatigue that even individuals without MS would be able to comprehend. On the other hand, fatigue specifically caused by MS, and referred to as *lassitude*, is thought to be in a category all by itself, apart from these other causes of general fatigue. *Lassitude* can happen in the morning after a



restful night's sleep, and tends to worsen as the day progresses. It usually occurs on a daily basis, can be aggravated by heat and humidity, and is more severe than normal fatigue. For now, it is unknown what causes *lassitude*, although it "does not appear to be directly correlated with either depression or the degree of physical impairment." (About MS, "Symptoms")

While *lassitude* appears in 80% of the cases of MS, it is in fact second to the even more pervasive symptom of immobility. Every case of MS is different, which is one of the reasons it is hard to diagnose and took doctors centuries to give it a name. Some people who live with MS will never need a mobility aid like a cane, walker, or wheelchair, while others are bedridden within a few years of contracting the disease. There are some medications that have developed over the years that can slow the progression of muscle loss, but many patients end up in a wheelchair full time. My mother has a relatively slow progression of the immobility caused by MS, and she was in a wheelchair full time 13 years after her diagnoses. Meanwhile, my grandmother was in a wheelchair full time only a few years after contracting the disease.

The first symptom usually experienced is numbness in the face, hands, feet, or other extremities. It can range from annoying to disabling, preventing the person from being able to dress themselves or walk. There is no known fix for the numbness, but doctors find that it usually fades away on its own. Numbness often serves as the reason a person initially goes to the doctor and subsequently gets diagnosed with MS, after a series of important tests. While there is no specific test that can diagnose MS, there are three important findings that doctors will look for in order to determine that it is indeed Multiple Sclerosis:

1. Find evidence of damage in at least two separate areas of the central nervous system (CNS), which includes the brain, spinal cord, and optic nerves AND

2. Find evidence that the damage occurred at different points in time—at least one month apart AND
3. Rule out all other possible diagnoses ([About MS](#), “Diagnosing MS”)

Unfortunately, the cause of MS is still unknown, although there seem to be three key factors that MS patients tend to have in common: immunological, environmental, and genetic. In a person who has MS, there comes a point in their lives when their immune system decides that the myelin in their Central Nervous System is bad, and needs to be destroyed. Much like our immune systems attack germs and common illnesses, the immune system in an MS patient attacks their myelin. Scientists have yet to discover why this happens, but it is largely assumed that the answer to that question will quickly lead to a cure and research continues to search for the answer.

MS seems to occur more frequently in places that are farther from the equator. Scientists have linked this occurrence with the lack of Vitamin D found in people who receive little sun exposure. Vitamin D has been found to benefit the immune system of a body, and the more exposure a person has to this vitamin, the less likely they are to develop any autoimmune disease. Meanwhile, genetics seems to play some role in determining a person’s chance of getting MS. Though it is not directly inherited, having an immediate relative with MS does increase your chance several times of acquiring the disease. Much research is focused right now on understanding the genetics surrounding this disease and others, and as our genes are better understood, so will the cause and transfer of MS. ([About MS](#), “What causes MS?”)

In general, MS is initiated and diagnosed in people during early adulthood, usually between the ages of 20 and 40. The occurrence of the disease is higher in women than men, but both sexes can be affected. Race also seems to indicate a person’s chance of getting MS as it “is

extremely uncommon among Asian peoples, unknown in African blacks, and relatively infrequent among African Americans” (Rumrill and Hennessy 6). Those of Germanic, Anglo-Saxon, and Scandinavian lineages are much more at risk, and this seems to coincide with the idea of distance from the equator and receipt of Vitamin D. (Rumrill and Hennessy 5-6)

Multiple Sclerosis has now been divided into four clinical courses of the disease, and each patient can expect to fall into one of them. The most common form is called Relapsing-Remitting. This is characterized by clearly defined flare-ups: times when there is an exaggerated worsening of mobility and muscle control, followed by other periods of remission when the disease has completely stopped advancing. Eighty-five percent of MS cases fall into this category. The second is called Primary-Progressive, and it occurs in only 10% of MS cases. It is characterized by a continuous, slow progression and worsening of the disease and its effects. As said before, however, each case is different and even this course can occur faster or slower depending on the person. ([About MS](#), “What is MS?”)

The third is called Secondary-Progressive, and it occurs in approximately 50% of MS patients. This can best be described as a combination of the first and the second courses; it begins with a period of flare-ups and remissions, followed by a long period of slow and steady deterioration. Some patients experience flare-ups even during the second phase. Finally, the fourth course is called Progressive-Relapsing, which occurs rarely in 5% of those diagnosed with MS. A person with this course would experience a steady worsening of the disease *and* attacks of severe nerve damage. Compared to any of the other courses, this course offers the least amount of periods of recovery or remission, as there seems to constantly be a worsening in either the acute or obtuse fashion. ([About MS](#), “What is MS?”)

The true effects of MS can be seen in the lives of those who live with MS and their families. A person with MS struggles with physical and psychological problems that, without a cure, will never go away even if they can be managed. There are several drugs available to help slow down or ease the burden of MS flare-ups, but each case is different and these drugs are not available to many patients who either don't know they exist or can't afford them. An important way of managing the symptoms of MS is rehabilitation. "Rehabilitation professionals focus on overall fitness and energy management, while addressing problems with accessibility and mobility, speech and swallowing, and memory and other cognitive functions" (About MS, "Treatments"). People with MS will need a life-long rehabilitation plan in order to manage pain, fatigue, and maintain the mobility left to them.

### **III. MS and the Creation of the NMSS: A Historical Perspective**

Knowing all of this, it is no surprise that a foundation was formed in order to help those affected by the disease. While the National Multiple Sclerosis Society was formed in 1946, this was not the beginning of goodwill directed towards those suffering from MS. It's impossible to pinpoint a place in time when Multiple Sclerosis appeared, but there are histories and written accounts of what can appropriately be assumed to be MS cases before MS had a name. One of the early accounts discusses a young woman known as Lidwina of Schiedam, Holland. She was also known as Lidwina the Virgin because she saw her growing paralysis as a chance to join in with the suffering of the Lord (at the encouragement of her parish priest, Father John Pott). She is described as going through several periods of paralysis, recovery, and bed sores and loss of sensation that accompany those, and soon her pious suffering gained public attention (Murray 23).

William VI, Count of Holland, and his wife actually sent their own physician to look at her: an important instance of public attention resulting in the wealthy aiding the poor (Murray 24). This is exactly what Robert A. Gross discusses in his article, “Giving in America: From Charity to Philanthropy.” Tracing the ideas of “charity” and “philanthropy” through the history of America, beginning with the colonists, he would say that in the case of Lidwina, she was receiving the charitable services of the Count and Countess, along with any aid she received personally from the people around her. Gross explains that, “Charity expresses an impulse to personal service; it engages individuals in concrete, direct acts of compassion and connection to other people” while philanthropy “sought to apply reason to the solution of social ills and needs” and “aspires not so much to aid individuals as to reform society” (31).

It is hard to come to the aid of people suffering from a disease with no name, and it wasn’t until the early 19<sup>th</sup> century that the concept of the disease that would eventually be named MS began to develop. In fact, Charles Rosenberg stated that, “A disease does not exist as a social phenomenon until we agree that it does—until it is named” (qtd. in Murray 103). Jean-Martin Charcot, a professor of neurology at the University of Paris, is often called the “father of neurology,” and is acknowledged as the first to officially write a “complete description of the disease and the changes in the brain that accompany it” (Rolak 2003). Charcot named this disease “*sclérose en plaque disséminée*,” referring to the *plaque* or scar tissue formed when the myelin is attacked (Murray 108). Drawing on the work of Charcot, more cases of MS around the world were unveiled and studied as the 19<sup>th</sup> century came to a close. In 1870, Wilhelm Schüle published a report on *multiplen Sclerose*, which was later translated as “Multiple Sclerosis” (Murray 141). So with the medical community growing in the scientific method and in its

knowledge of this neurological disease, the stage was set for an organization to give a helping hand to progress.

The National Multiple Sclerosis Society didn't come in to play until the middle of the 20<sup>th</sup> century, when a concerned sister put an ad in the paper on behalf of her MS-stricken brother. Sylvia Lawry, in concern for her brother, placed a classified advertisement in *The New York Times* in 1945, reading: "Multiple Sclerosis. Will anyone recovered from it please communicate with patient" (About the Society, "Sylvia Lawry"). When she received only responses asking for more answers and help with dealing with this disease, she chose to coordinate an effort to improve communication and thus aid the research being done. So on March 11, 1946, Lawry started the NMSS by gathering 20 research scientists to pursue more information and eventually a cure. The mission statement of the NMSS follows Lawry's lead, as it aims to "end the devastating effects of MS." She devoted the rest of her life to developing this organization and promoting its philanthropic mission. From humble beginnings, the NMSS has grown into the leading philanthropy for MS in America.

From the start, the NMSS was focused on aiding research so that advancements could be made and a cure could be found. The very first research grant awarded from the Society was used to further the study of the "relationship between the body's immune defense system and the impact of MS on the central nervous system" (Rolak, "1940s: The coming..."). The broadly categorized neurological disease of MS was becoming more focused and understood already. Over the next few years, grants were awarded to scientists in 17 different countries who were studying everything from description to diagnoses, from finding a cause to searching for a cure (Rolak, "1940s: The coming...").

In 1950, the NMSS advocated Congress to establish a special section of the already existing Nation Institutes of Health called the National Institute for Neurologic Disorders and Stroke (NINDS). The NMSS now had a powerful partner is promoting neurological research that still supports nearly every major MS study proposed by the Society. Unfortunately, as research progressed in the laboratories, the knowledge of local doctors remained the same, and MS patients were still being treated for impaired blood flow with little results. The disconnect between philanthropy and people it is ultimately trying to serve, however, is exactly what Gross discusses in his article. He says that, “It’s [philanthropy’s] achievements were purchased at an unacceptable price: the personal charity essential to any decent community” (46).

Lawry did not so easily forget the need of individual cases, however, and as research was steaming ahead in the 20<sup>th</sup> century, the NMSS was setting up chapters across the country that could better serve the people with MS and their families. By 1960 the Society had established 114 local chapters that provided services such as “education, counseling, self-help, equipment loan” and more (About the Society, “Sylvia Lawry”). As the NMSS grew in both its research efforts and its charitable aid, the former began to confuse the latter. As the results from the research being sponsored around the world trickled into the NMSS, MS patients were unsure what to believe, what new treatments to search out, or even was what was scientifically established. To combat this, the Society “funded a panel of experts, headed by Dr. George Schumacher, to draw up standard guidelines for MS diagnoses” (Rolak, “Chaos addressed...”). These standards, refined but still in use today, helped doctors treat MS patients more accurately and diagnose them sooner; they helped to lessen the disconnect between philanthropy and charity.

Lawry continued to develop and work at the Society even up to her death in 2001. She was the instigator of a philanthropic organization that has devoted more than \$600 million to MS research since 1946 and serves over one million people. The efforts of the NMSS span from advocacy to education to personal counseling to worldwide coordinated research. It truly embodies the heart of Gross's article, and I think Sylvia Lawry would agree with him when he says, "Without a compelling social program, charity can dissipate into transient encounters between unequals. But without direct, mutual bonds between givers and recipients, philanthropy sacrifices practical effectiveness and moral purpose" (48).

#### **IV. Doing Good: A Theoretical Discussion**

Lawry devoted her life to the cause of Multiple Sclerosis because she was close to someone who had it: her brother. What about starving children in Africa...or even downtown New York City? Can it be said that Lawry made the right choice by dedicating her life to a single cause...a single cause that she would benefit directly from the outcome? Is that true charity: to raise money, increase awareness, and devote one's entire life to seeking answers for a family member, for oneself?

Patricia Werhane discusses this very issue in her essay, "Focused Fairness in Philanthropy." She argues that we often give our time and money to causes that pique our interest, or ones that we have personal involvement in, rather than considering "which can benefit best with our dollars or services, and how best to distribute these benefits" (84). Is personal attachment a good reason for deciding who and how to help? To answer this question, Werhane refers to the work of Immanuel Kant, an eighteenth-century philosopher who said that "it does not matter to whome (sic) one is benevolent and philanthropic" as long as it is done with "the right motive—out of a sense of duty, with recipients treated with dignity and respect" (89).



Kant is a realist who understands that when we help one another because we have a personal interest in the cause, we are more likely to put forward our best energy toward the cause, and this will allow the most good to be done.

Still, even Kant refers to a need to have some kind of system of evaluation in order to determine that one's motivation for doing good is in the right place. He offers three moral principles: "duties to respect autonomy, duties not to harm, and duties to aid" (Werhane 89). However, in the *Theory of Moral Sentiments*, Adam Smith replies to Kant's principles with the idea that one can be well-intentioned, with a perfect sense of moral duty, and yet not be achieving the most good he could. He explains that "at least part of that determination has to take into account the considered preferences of those we are trying to help, what they take to be basic needs, which social good they might consider as enhancing their well-being, and the core values they share in their particular society or sub-culture" (Werhane 90).

If Sylvia Lawry had started the NMSS based solely on the needs of her brother alone, there would have been a lot of MS patients left in the dark. Every case of MS is different, and researching cures based on Bernard Lawry's symptoms alone would have stunted the project from the beginning. However, Lawry saw the need for the aid of an entire community; she heard the cries for help in the responses she received from the classified ad and sought a way to aid their need for support, medical aid, and hope for a cure. Werhane questions, "Are we to give preference to the principle of producing as much happiness [or reducing as much suffering] as possible, or to the principle of spreading it [our largesse] as widely as possible?" (92). Sylvia Lawry successfully accomplishes both by focusing on one cause and addressing all of the issues within it. She coordinates worldwide research in the hope of one day releasing everyone from

the burden of this disease, and she establishes local chapters to address the day-to-day issues of people with MS and their families.

Still, Werhane insists on a “principle of fairness to evaluate philanthropic activities, and...distributive criteria for that form of giving” (93). She calls this principle “focused fairness” and establishes four criteria for evaluating the “good” of philanthropic activities. The first is to evaluate the worth of the project: “one has to measure the need of the recipients and the satisfaction of that need per dollar given” (Werhane, 95). For example, there are telemarketing businesses that are run using the name of well-known philanthropic organization like the American Cancer Society. They rent an office, hire employees, and make calls to everyone in the phone book trying to get people to make donations to the ACS. Unfortunately for those who are unaware, upwards of 90% of each dollar they donate is going to the business and to the employees while a mere 10% is actually going to aid the cause of cancer. Meanwhile, the National Multiple Sclerosis Society spends only 6% on administrative costs, 15% on fundraising, and 79% on programs that range from counseling to education to research (Give.org). It is clear which of the two Werhane would consider worthy of a person’s money and dedication.

The second criterion of Werhane’s “focused fairness” is to determine if the people one is attempting to help are worthy of receiving such aid. This is not to exclude those in need, but rather to ensure that limited resources are reaching those most deserving. Werhane suggests a “focused distributive justice” that takes “into consideration what is deserved, (needed), or due in the pool of individuals, agencies, or foundations under consideration to receive philanthropy” (95). However, what is “due” to this “pool” is not only guided by preferences and cultural differences of the pool, but is also restricted by the mission of the philanthropy. The NMSS aims to end the devastating effects of MS, and has thus opened itself to an endless array of options to

“do good.” The NMSS provides services ranging from counseling affected families, to providing financial assistance to members who cannot afford medications or mobility services, to national and international research coordination. It provides such services as they are needed and in tandem with its mission statement.

The third criterion of “focused fairness” states that “in working toward ‘fair’ distribution, the individuals, agencies, and foundations with limited funds have to set priorities” (Werhane 95). There is a non-profit organization based on the Web called Computer Literate Advocates for Multiple Sclerosis or CLAMS. It is a small non-profit that aims primarily to “to bring those with MS out of isolation and into computer communications for support, companionship and information with others sharing this disease” (CLAMS). It follows Werhane’s advice to “define their mission narrowly” (95). CLAMS is aiming to use computer technology to give MS patients greater access to information and support, which is first of all a worthy project and second of all aiming to make technology available to everyone. It has set its priorities clearly, and does not attempt to cure MS, raise \$100 million dollars, and put a brand new computer in every home affected by MS. It has declared its intentions narrowly, and will more likely reach its goals and thereby do the most good because of it.

The final qualification for “fair selection and distribution is that of measuring the efficiency and effectiveness of delivery mechanisms and use of funds” (Werhane 96). There are several ways of measuring an organization’s use of funds, some that are from within the organization and some that are from objective outsiders. The website “Give.org” is an important website for potential philanthropists to see how a non-profit has measured up against its 20 standards. One can view financial breakdowns, executive board salaries, and program information. Inside an organization like the NMSS, where the goal is complete transparency,

financial breakdowns are published yearly in mailings or publications as well as available on their website. Evaluations are done on a regular basis, and distribution adjustments are made accordingly. These tools continue to be used by non-profits who seek to measure their effectiveness in order to ensure they are accomplishing their goals, and doing good with them.

While Werhane's steps to achieving "focused fairness" sound practical enough for the individual philanthropist, can they be applied to an organization as large and complex as the National Multiple Sclerosis Society? It's hard enough for individuals to ensure that they are doing the most good with what they are willing to give, but how can they be sure that the organizations they are giving to will do the most good with what they gives? How does an organization like the NMSS spread out its funds and resources? These are the questions that brought me to the office of Tiffany Bogard, the President of the Indiana chapter of the NMSS.

## **V. Doing Good: A Practical Application**

I first contacted the National Multiple Sclerosis Society with a simple email, explaining the intent of my project and my hopes of being granted an interview. Instead of theorizing about how to apply Werhane's four qualifications for "focused fairness," I wanted to apply them to an organization and see how it passed the test. After being transferred from one contact to another, Ms. Bogard sent me an email expressing her desire to contribute to my project. While I had been in contact with a secretary of the Indiana chapter of the NMSS and its Director of Finance and Administration, I was delighted to see that the President of this chapter had been so willing. We conversed through emails, and Ms. Bogard scheduled me into an hour slot of her schedule. I drove to Indianapolis, where the Indiana chapter headquarters are, and met with Ms. Bogard in her office. (The questions that guided my interview, and a transcription of the interview itself, can be found in Appendix A.)

I began our interview by asking Ms. Bogard how she came to be involved in the NMSS, how she evaluated this nonprofit to be worthy of her time. She explained that while much of the staff at the Indiana chapter has a personal connection with MS (friend or family), she and other staff members did not. She began in the HIV/Aids field of nonprofits 18 years ago, moved to children's issues, and saw an opportunity to at the NMSS and took it. Spending the first four years as the Director of Chapter Programs, she has been chapter President for the last three. Ms. Bogard explained that while the staff is a combination of those with immediate MS connections and those not immediately affected, the clients and supporters of the NMSS are generally a self-selected pool with personal ties to MS. She said, "the estimate is that for every one person that has MS, there are seven people affected by the disease." So even though there are only about 400,000 people specifically diagnosed with the disease, there are close to 3 million family members, employers, doctors, and friends that are significantly affected. She said, in her experience, that "most of the time with a health-related issue, people support it because they have some sort of connection."

For example, Crocs, Inc. is working with the NMSS right now to raise money for MS by selling special Crocs shoes with the NMSS logo. For each pair sold, Crocs will donate \$2 in support of the organization. When I asked Ms. Bogard how this came about, she said, "it's not something that we spend a lot of time to go out and say, we want to try to see who we can partner with, but if there's a connection, if there's someone at Crocs who's high level and has MS obviously we'll have those conversations." However, there are plenty of ways people get involved with little to no connection at all. The NMSS state chapters host Walk-MS and Bike-MS fundraisers, and while the majority of these events are participants with personal connections to the disease, they can attract others as well. Ms. Bogard said, "the cycling event is probably

the one that has the more non-MS Society constituents than any other event...because cycling is big in a lot of places.”

Werhane speaks of the worthiness of an organization fulfilling a “utilitarian qualification: that of achieving more help to more needy per-dollar than other alternatives can provide” (94). With all these fundraisers happening simultaneously across the country, how can donors be sure their money isn’t going straight back into the events themselves? Ms. Bogard said that the overhead at events like the Walk-MS walk or Bike-MS events is very minimal, and many materials are even donated. Fundraisers like the NMSS Women against MS luncheons, however, usually incur more overhead, since a chapter will have to rent a location, and will often sponsor a celebrity like Montel Williams or Clay Walker to speak. Ms. Bogard said, “the return on that, you know, hopefully makes that worth your while...but as a national office, and as a chapter, our certification requirement is that we have to be 25% or under in our management and fundraiser expense. As stated before, the website “Give.org” puts the NMSS right at 25%, combining the fundraiser and administrative costs.

In America alone there are over a million nonprofits (Hall), and not only does the NMSS have to find donors who consider their organization worthy, but they are also competing for grants from organizations like the National Institutes of Health. Ms. Bogard said, “grant funding is a challenge for us, because a lot of people want to consider they’re focusing on statewide or local funding, and if you’re a national organization, they think that they’re [grant committees] funding the national office.” The committee members who make grant decisions want to know the same thing that Werhane’s second qualification asks: is there fairness in distribution? How can the everyday donor know that his or her dollars aren’t just going to fund the head office?

Ms. Bogard explained that first, it depends on if the gift is restricted or not. If a donor has a specific purpose for giving, he or she can restrict the donation to reach only places he or she intends it to. Otherwise, money raised through fundraisers, special events, and donors is split 60/40. She said, "Sixty percent stays with the local chapter...forty percent goes to national, and since we don't fund research on the local level, some of that forty percent goes to fund the \$45 million a year we spend on research." This split is important to Werhane's second qualification because it allocates funds towards the NMSS mission, and also takes into account the specific needs of the "pool." Not only is the money going to the national headquarters to fund research, but also to fund program initiatives that are based on advanced technology and undertaken solely by the national office with a goal of benefiting state and local chapters. These initiatives can include web access or national teleconferences that report research breakthroughs, a VHS or DVD program that members or chapters can use to educate, and even efforts to improve the costs and efficiency of the administrative support the national office provides.

With such a diverse and complex system of organization, how can the NMSS follow Werhane's third criterion: to set priorities? Werhane is referring to agencies and donors with limited funds, but so too can an organization like the NMSS, with an operating budget of over \$200 billion easily lose focus in maintaining its budgetary goals unless the goals are stated clearly and prioritized (Give.org). As stated earlier, the mission statement of the NMSS is "to end the devastating effects of MS." Ms. Bogard admitted that this is vaguely defined, but that is because the devastating effects are widely varied. For example, one of the ways MS is devastating is financially. She said that over 50% of people with MS quit working within 5 years of their diagnoses, and living with MS is estimated to cost around \$60,000 a year. So, as the result of

nation-wide survey taken in 2005, a list of five, more narrowly defined goals was developed in 2006:

1. We are a driving force of MS research, relentlessly pursuing prevention, treatment, and cure.
2. We address the challenges of each person whose life is affected by MS.
3. We mobilize the talents and resources of the millions of people who want to do something about MS.
4. We are activists.
5. We will raise a total of \$1.25B by the end of 2010 to be used in the fight against multiple sclerosis. (2006 publication of the NMSS)

Ms. Bogard said that they attempt to reach their goals and live up to their mission statement by meeting their clients where they are. The NMSS offers case management, so that if somebody needs financial assistance, they can do that. Advocacy is another way the Society works towards their goals with things like MS Day on the Hill where people from every chapter volunteer to go and advocate for MS issues. For example, there is a 25-30 year old Medicare restriction that refuses funding for mobility aids like wheelchairs and scooters to people who don't *need* it inside their home. Unfortunately, this doesn't acknowledge that many people with MS don't have wheelchair accessible homes and, in fact, may be fully able to "get by with a cane or walker, or walking along the wall in their home." Ms. Bogard added, however, that given how debilitating fatigue can be, these same individuals might still be dependent on a wheelchair outside the home, when they are "going shopping, or they're going to work and it requires them parking and walking into a building or even getting into the building and walking a considerable amount of time till they get to their desk." In this regard, Ms. Bogard explained that the home-



use requirement is based on a misconception within the general public that a person in a wheelchair or scooter can't walk at all. However, with MS that's not always the case. As a result, she noted, "we have for a long time tried to get [the Medicare] restriction lifted; there's a lot of opposition to that though because there's a high level of fraud in the Medicare program."

With such a range of long- and short-term goals, I asked how the Society makes sure that they are accomplishing all of their goals. Ms. Bogard replied that the national office concerns itself with the long-term goals, and that primarily entails researching for a cure. She said, "those at the higher levels of the organization are very focused on the strategic issues: the long-term, the vision, making sure that what we're doing now continually moves into the strategic plan." However, she said, "they define maybe the top priorities for us, and then locally we take those goals and we develop our own strategic plan about how we're going to implement those things." So it becomes the individual chapters' responsibilities to decide how to best serve the MS community around them.

This decision is why Werhane concludes that there needs to be a way of measuring the efficiency and effectiveness of philanthropy. There are several different ways in which the NMSS has made sure that it is continuously serving its communities efficiently. Ms. Bogard said, "every few years we do a local needs assessment, and we'll send that out, ask people what...we should be focusing on, because it [needs] varies from chapter to chapter." As mentioned before, however, in 2005 there was a national survey done by the head office that asked this question: "If you had a dollar to spend on MS, how would you break that down?" Every client and donor was given surveys, as well as board members, volunteers, and any one who had an email or mailing address in the database. The results of this survey were challenging to those working at the NMSS because it forced them to reorganize a lot of their priorities within

the organization. Ms. Bogard said that the results were all over the place, and the surveys implied funding should really be split up into several different areas, which resulted in the five goals mentioned earlier.

Ms. Bogard referred to their budget as a “fluid document,” and said that it changes every three to four years. There isn’t an assessment done every year, but as mentioned earlier, the goal is “full transparency” and the financial records are public knowledge. So when an assessment is done, a strategic plan is formed in order to meet the needs revealed by the assessments, and these usually go three to five years. Also, However, Ms. Bogard reminded me that the ultimate goal of a nonprofit organization like the NMSS is to go out of business and she said, “Maybe, you know, we’ll find a cure. Well obviously that will change everything. You know, we won’t need to do as much education, we’ll need to do more symptom management, things like that.”

## **VI. Conclusion**

The main goal of this project was to explore the moral issues facing donors when deciding how best to use their money for good, and, consequently, the moral issues facing a nonprofit organization like the National Multiple Sclerosis Society when considering how best to distribute the dollars they receive from donors. My paternal grandmother often complains about the ten phone calls she receives a day from various organizations she has given to in the past asking for more money. She keeps a notebook full of dates and dollar amounts so that when one of them calls, she can say, “I already gave \$10 in February, and that’s all I’m able to give at the moment, please call back next year.” She gives to causes of all kinds depending on her interests and what her friends or family members might be going through.

My grandma can’t be the only one in America today dealing with charitable telemarketers, and it can be hard to hang up on someone who is asking for money to feed poor

children in Africa. However, it would be helpful to have a way of making sure that well-meaning donors like my grandmother are actually doing the good they think they are. This really hits at the heart of my project, and I think that the idea of “focused fairness” and the four qualifications Werhane offers are a good place to start. Knowing how to research an organization on websites like “Give.org” can also be extremely enlightening, but for those who might not be very technologically savvy, simply asking the telemarketer for the percentages of fundraising and administration costs would be a good start.

This is why I wanted to do a practical application in the course of this project, not just write a paper and have it sit on the library shelf for the next 60 years. First, I wanted to actually attempt to do some good of my own, rather than talk about doing good, and so I set up a Memorial Fund website through the NMSS in honor of my maternal grandmother and namesake, Winifred Lorraine George. This is a gathering place for those who might want to join with me in my efforts to raise money for the NMSS, and I have sent out a letter, found in Appendix B, to all my friends and family letting them know about the Memorial Fund website. I also wanted to pass along the information this project has revealed, and I developed a “Guide to Giving” that can also be found in Appendix B. This guide summarizes my project, Werhane, and the NMSS in order to share with my friends and family the ideas expressed in this paper.

When my friends and family choose to be philanthropic, I think the most important conclusion from this project is that they give where their heart leads them to give. There are millions of ways to do good, and if we each contribute to this world in the way we feel connected and let to, then the needs of our world are going to get met at least in a partial degree. David Craig explains the effectiveness of this when he says, “this deeply personal element in

philanthropic motivations and aims helps account for a key feature of giving in the United States today” (60).

Another important conclusion from this research is that individuals might want to take the time to research the organizations to which they are considering giving their money. A philanthropy with honest aims and achievable goals will follow the NMSS’s lead in wanting to be fully transparent. If nothing can be found on the website “Give.org,” or any other evaluative source, give the organization a call and ask. Ms. Bogard said that for the NMSS, “[the information is] out there if you know where to look, but if you don’t know where to look you can certainly call and ask.” Taking the time to know where your philanthropic contributions are going suggests a thoughtful, not an unduly skeptical, approach. Your research into a given organization doesn’t make your effort to do good any less; in fact the four principles Werhane describes would suggest otherwise. Her principles are in place for the very purpose of making the most difference in a fair and practical way.

Finally, I conclude that the National Multiple Sclerosis Society has proved itself to be worthy of the time and money people give to it. They are seeking to make a difference in all aspects of the lives of those affected by MS, and they are doing it in a thorough and morally sound manner. As the object of a case study of moral issues in giving, it has passed the test and come through with flying colors. This case study, and the NMSS, can now be used as examples in order to determine other worthwhile causes so that we can continue to improve the lives of others and truly “do good” in the world around us.

# Appendices

## **Appendix A:**

### **Interview Questions for Ms Tiffany Bogard, President of the Indiana Chapter of the NMSS**

1. What is your story? What is your personal connection to MS? How did you come to work for the NMSS?
2. The mission statement says you aim to “end the devastating effects of MS.” Explain how the Society balances the many avenues of achieving this goal.
3. Is there one goal that receives more attention than the rest? If so, how did the NMSS decide that this was more important than the others?
4. How do you divide time and funds between your short-term goals and your long-term goals?
5. Explain how the NMSS is organized in terms of chapters, and how this affects donation distribution.
6. How do you measure that you are doing the maximum amount of “good” with the money you receive?
7. How do you demonstrate to donors and potential donors that the NMSS is worthy of their donations, when there are so many others vying for their money as well? How do you convince them that their money should go towards MS research rather than breast cancer or natural disaster relief, for example?
8. Have the other non-for-profits that raise money for MS had any impact on your membership levels or budget?
9. It doesn’t seem like there are celebrities advocating for MS quite as strongly as, for example, Lance Armstrong does for cancer. Is this true? Does the NMSS wish there were celebrities working for the cause?
10. How can donors be assured that you are using their money wisely and are making the most difference possible?
11. How is your budget affected by national and international disasters like Hurricane Katrina?
12. Selling items with the understanding that a certain amount of the purchase price will go towards a “good cause” is a very popular trend right now. The NMSS seems to be participating in this trend in several ways with the Crocs and local artist donation. What is your opinion about this way of fundraising? How does this contribute to awareness and fundraising?
13. How did the NMSS begin the MS Walk/Ride, and why did it become such a staple in the yearly fundraising process? How does it meet the goals of the NMSS?
14. What is the Action Alert Network currently advocating for in public policies? What major influences has the Network had on public policy in the past?

## **Transcription of Interview**

Interview with Ms Tiffany Bogard, Indiana Chapter President of the NMSS  
Wednesday, February 13 at 12pm

Me: So first I just wanted to know if you had any questions for me to understand what my project was about.

T: What is you degree in again?

Me: Um, it's in Spanish and Religious Studies and so it's completely unrelated to this, basically. But I took a class from a professor at one point and it was talking about nonprofit organizations and how donors decide where to give their money and how those organizations convinced donors basically that their place was the right place for their money. And so it's mostly talking about how a person or an organization decides where money goes and how to do essentially the most good with the money they want to give or are receiving.

T: Now, tell me cuz I don't remember if you told me this, cuz your email got forwarded to me from somebody else. So tell me how you got interested in the MS Society

Me: Um, My mom actually has MS, and her mom had MS...and I never knew her, she died when she was pretty young. And so, it's been a huge thing in my family and so studying this issues, we...me and my advisor decided to pick an organization to do like a case study of to study the issues within this one organization. And so I wanted to learn more specifically about MS, and through my research I get to learn more things that my mom never really taught me about cuz it was too emotional for her to deal with.

T: Is she doing okay?

Me: She is doing better than she has...she's had it for 26 years now, and so um, when I was a senior in High School she actually got really bad with it. It was not really the MS, it was that she had to have surgery and the surgery didn't heal for like three years, and so that's really what caused most of the problems. She's able to get up and out of bed now which is a big improvement from where she used to be. And we're actually going on a cruise next month.

T: is she local?

Me: She's in Kokomo, actually.

T: Does she do anything with the society?

Me: She said that she was a member, and I think she gets like a magazine, but growing up I never really heard that much about it no.

T: Well, you can always welcome her to the fold, she would be welcome.

Me: I will let her know that, I'm sure she would love it.

T: Alright, so do you want to just ask me, or should I just run through these questions?

Me: Um, I can ask, that's okay. Um, my first question is just how did you get involved in the Society and what's your story with it?

T: My story. Um, ya know I...we're pretty split here at the staff. We have about 14 or 15 people on staff. We've got four community development managers who work outside the Indianapolis office, and then everybody else works here at the Indianapolis office. We're pretty split about people who have come with really not a lot of connection, and people who either have MS or have a family member, uh a close connection with the disease. And I actually did not really have a connection with the disease. Um, my story is that I've been in nonprofits for about 18 years. I uh started in the HIV/AIDS field in the 90s and worked there for a long time, so I worked with the disadvantaged health-related population. I've been moved to children's issues: disadvantaged children, impoverished children. I was the director of a state-wide children's mentoring program, and then I was looking for an opportunity when this one happened to open up. So, I did, I do have an aunt...a former aunt, she was married to my uncle but they've gotten divorced, who has MS but we're not real close. So I knew what it was, but I wasn't real connected. I've been here for 7 years.

Me: And what position did you start out when you joined here?

T: I started out as Director of Chapter programs and was doing that for 4 years, and then almost 3 years I was promoted to chapter president.

Me: Okay.

T: I will give you my card while I'm thinking about it, so if you have any questions along the way you can get in touch with me.

Me: Thanks. The mission statement says that you aim to end the devastating effects of MS. Can you explain how the Society kind of balances all the different areas that addresses?

T: Well, as you might know, the devastating effects of MS is pretty vaguely defined. It can be different for anyone. It can be different for any client and it can be different for anybody who's affected by the disease through a family member. Um, MS can be very financially devastating, and of course it can be physically devastating. Um, a lot of people...a statistic I heard once, I don't know if it's true, it was quoted to me by a nurse so I would think it was true. But she said, over 50% of people with MS quit working within 5 years of their diagnoses, and that is startling to me. And this was several years ago so I don't know if that's still the case, but um...when you look at the fact that only about 25% of the people who have the disease are taking the medications that are out there to slow the progression, I wouldn't be surprised if it was still close to 50% that are uh, not working. Um, a lot of times when people stop working or lose their employment, they then lose their health insurance connection. And so, the financial implication, it's about \$59-60,000 a year, they estimate the cost of having MS between the medications,



insurance, doctors, things like that. So, um, and that varies if it's loss of wages as well. So what we try to do is meet each client where they are. We offer case management, so if somebody is coming to us and they need financial assistance, we do that. If somebody needs education, we do that. If somebody needs, um, we have a huge research, um, fund every year. We are the largest private funder of MS research in the world...the MS Society is. So, research is a big component of it. Advocacy...um, helping to get increased research funding, helping to get better insurance for people, Medicare coverage, things like that. So really through programs, services, research, and advocacy are our main things. Those are very client-centric. We also do a lot with raising awareness, PR. We have special events to help raise money but also to educate other people about the importance of the disease.

Me: So I hear you saying that, um, kind of...I guess in terms of like the overall picture, you try to um, decide where your funds go to based on client need, on who comes to you?

T: Yeah, a couple years ago we did a national survey and we said...we surveyed all of our clients, all of our donors, all of our board members, volunteers, anybody who was in our database who we had an email for. And um, this was national, it was in 2005, so it was almost 3 years ago...we said, "IF you had a dollar to spend on MS, how would you break that down?" And before that we had a very clear idea of this is how we think we need to spend our dollars, and after we got that survey it was all over the place. Ya know, some people said the whole dollar should go to research. Some people said the whole dollar should go to programs. Some people said it should be split up evenly among six different categories, so that really changed our focus and we developed a national strategic plan with five main goals that I can talk to you about later. But, uh, they have identified the priorities, and so since like I said, end the devastating effects of MS is so vaguely defined, and we wanted to keep it that way because it means something different to everyone.

Me: So does it change, on a year to year basis...or 5 to 10 year basis on whether such a percentage of your budget goes towards research or towards programs or education...

T: I would say it changes every 3 to 4 years, that's an estimate. We don't do a needs assessment every year, but we do a strategic plan, that usually, ya know strategic planning usually goes three to five years. So, of course our plan is a fluid document, if we come back next year, okay what we came up with last year just isn't working for us ya know, maybe something will change. Maybe, ya know, we'll find a cure. Well obviously that will change everything. Ya know, we won't need to do as much education, we'll need to do more symptom management, things like that.

Me: Is that on a nation-wide basis, or is each chapter, kind of trying to...

T: Nationally, they define maybe the top priorities for us, and then locally we take those goals and we develop our own strategic plan about how we're going to implement those things, hopefully.

Me: Um, is there one goal that receives more attention than the rest? Like, research or education?

T: We have five main goals right now...and I do have this document for you, but it gives you a little bit of an idea of what our top five goals are. And, I'll just read them to you so you have them for your recording. "We are a driving force of MS research, relentlessly pursuing prevention, treatment and cure." So research is a main goal. "We address the challenges of each person whose life is affected by MS. We mobilize the talents and resources of the millions of people who want to do something about MS." That's mainly about volunteerism. "We are activists." That's self-explanatory. "We will raise a total of 1.25 bil dollars by the end of 2010 to be use in the fight against Multiple Sclerosis." So those are our five main initiatives and then we define those locally how we're going to educate people.

Me: Um, so in terms of the national, um, the head organization. How does the money get divided? The money that gets donated from people...does it stay within the state? Or does some of it go to the head office?

T: It depends on if the gift is restricted or not. The main split is 60/40. So any kind of general revenue, 60% stays with the local chapter...40% goes to national. And since we don't fund research on the local level, some of that 40% goes to fund the \$45mil a year we spend on research. Um, we also have some national program initiatives that come through, ya know, very high tech programs that we don't do locally. Maybe like, web access or national teleconferences, or they do a national video tape and DVD program that we subscribe to. So, the national programs support comes through that, as well as any administrative support is part of that 40%.

Me: So some of the goals sound like they're long-term, like "cure MS" and some of them are clearly short-term, like help the people who don't have jobs to find financial support. How do you, um, how does the Society organize its time in dividing its time between the long-term and the short-term goals.

T: That's a good question. I would say that it comes not only from the different levels of the organization, for instance, those at the higher levels of the organization are very focused on the strategic issues: the long-term, the vision, making sure that what we're doing now continually moves into the strategic plan. Um, make sure we're staying on track. And then, ya know our managers and our coordinators are doing a lot of the direct service, a lot of the short-term things. So, I would say, that as a staff that's how it's divided. Um, and that really is...uh, left up to individual chapters, I think to make that determination.

Me: Okay...um, when you go over...you said something about a um, an evaluation, the email you sent out..."what would you do with a dollar"...is that something you, is that the first time that's been done? That survey?

T: I think that's the first time that particular survey was done, and that was because we had a new national CEO that came in and um, she wanted to make sure she was reaching out to all the constituents. We have done local needs assessments as well, because that national survey isn't of course going to tell us what our local constituents want. So, every few years we do a local needs assessment, and we'll send that out, ask people what they think priority-wise, we should be focusing on. Cuz it varies from chapter to chapter.

Me: Okay, um...with so many non-for-profits out there vying for people's money...what kind of things do you do to, I guess kind of convince the public that this is a worthy cause and this is where their dollars should be going?

T: With, um, with the MS Society, ya know the estimate is that for everyone one person that has MS there are seven people affected by the disease. Through your family, your children, your parents, your employer, your doctors. So, even though there may be 400,000 people registered with the MS Society across the country, ya know there's close to 3mil people that are considered affected by the disease. So, my experience in the non profit community has been, that most of the time with a health-related issues, people support it because they have some sort of connection. And that's what I've found here, and so...most of our supporters are people who have a personal connection, either a friend or themselves, affected by the disease, and that's...so that's really the best marketing. Ya know, to target those people. As far as other competition for funds out there, ya know grant funding is a challenge for us, because a lot of people want to consider they're focusing on statewide or local funding, and if you're a national organization they think that they're funding the national office. Even though if you're saying, well the money's going to this, to these 10,000 people here in Indiana...so that has been a challenge for us to get that, because there's really not that personal connection. But we do receive a lot of money from pharmaceutical companies who have a personal investment in MS treatments. Um, we've received a lot of money from people who attend our special events, I would say 70% of our funds come from our special events. Those are people who, it's not the general public that's coming to the special events it's people who are there to support somebody who has MS.

Me: Can you further explain the pharmaceutical companies part? How are they...um, are they donating drugs, are they donating money?

T: They don't donate drugs to the Society, we don't distribute any kind of medication. All the pharmaceutical programs, actually probably every pharmaceutical company out there, not just MS, but they have patient assistance programs. So they will work directly with people if people can't afford their medication and that's separate from the MS Society. Um, but they donate funds to us to sponsor our special event, to support our programs, in return they get a little publicity and so they get their name out to people who may be considering taking a treatment.

Me: Okay, um, have you noticed any kind of...I hate to use the word "competition" cuz I mean you're all trying to help people, but have you noticed any kind of competition with other organizations that are trying to raise money for MS?

T: Um, very minimal. Um, the national MS Society is...is basically the #1 (lol) MS organization...if you do a Google search on MS the last time I did it, ya know 13mil things came up and the National MS Society obviously was first. So um, I would uh, I would say it's very minimal. The main thing is...it's confusing to people. Ya know, there are some communities where there may be another MS organization based, and it's hard for the general public to know what the difference is. There's a lot of confusion, I mean we have a group down at Southern Indiana that, ya know people think that we're them and they're us. So that's the most annoying thing, but it's not a competition as much for funds. Um, and then as far as...the

prevalence...there's just such a handful of them. Ya know, they're not as prevalent as the chapters of the MS Society. I know that there's another MS organization and they had, I think, one staff person to cover three or four states in the Midwest, so...I'm not concerned about that, ya know? And then, primarily we, we don't, obviously...mind that there are other organizations out there, the only thing we want to make sure is we're not duplicating services and thus having a bigger problem with um competition for funds. I mean as far as I'm concerned, the other MS organizations that I know about they just provide different services than we do. And we'll actually refer our clients to them if they provide a service we don't, but as far research goes, none of them do the level of research that we do.

Me: Do you work together with them at any point? Have...since your research abilities seem to be greater than theirs, do they every raise money and then say, "Okay this is going to go to you guys since you have better funding?"

T: I would say, that that probably does happen but not to a large extent. Um, uh...I think it's Montel Williams has a foundation and all he funds is research. And, so all of his dollars go to research because he, he's, he doesn't...and this is just my personal opinion, but I don't think Montel needs the services that we offer. So, and he can afford those kinds of services. So, his main thing is he wants a cure. So he has developed his own foundation, so if you were to raise money he would ya know send it to his foundation. Um, the other MS organizations, I think it's so hard to raise money that I wouldn't see them necessarily send a research gift to us. But ya know I think it's happened enough...we try to work collaboratively in the sense that ya know we always have a seat at the table and we always have an open door and we're doing more national collaborations with the heads of those organizations. But there are some that don't want to come to the table and so we, we just...bless and release, lol.

Me: Yeah...speaking of Montel Williams... he, as far as I'm aware is the biggest celebrity that's really pushing, that has MS and is pushing for research. I mean there doesn't seem to be a celebrity spokesperson, I guess, like Lance Armstrong is for cancer...

T: Well, first of all...cancer's such a much larger disease. And, uh, and Lance Armstrong...I mean you're right, but Lance Armstrong...Livestrong is, my understanding is they're raising money for cancer of all forms...it's not just one certain type of cancer. So, that's even bigger than even say breast cancer, because he's incorporating ever kind of cancer. And he is huge...um, he's a great, wonderful, powerful spokesperson. I would say Montel's prolly the biggest spokesperson of his generation...um, ya know, for my parents generation...um, ya know Annette Funacello she has MS, she's been out there with that for a long time...she was one of the Mousekateers. And uh, uh, Clay Walker who's a big country music star has MS, David Lander who was Squiggy in Laverne and Shirley has MS...I would say that "yes" Montel for this generation, but there are more coming out. Terry Gar's a big one, again from my parents generation.

Me: Has the Society tried to, I don't know, in a way used celebrities like that in order to gain more, um, just...people around America who even have heard of MS. Have they been trying to maybe work with celebrities in order to make it more well known?

T: We have...yeah we've worked with all of them basically on the level of raising awareness and helping to raise funds. Um, most of it probably has been with our, our luncheons. We have some Women against MS luncheons, and they'll go around and speak at the luncheon and raise awareness or raise money. And it rotates, um, ya know the face of MS is again hard to define, because it's different for everybody. Um, and so we are constantly trying to choose different advocate to represent the different levels of MS.

Me: Okay...um, if I were a donor who was giving a certain amount of money to the Society, how would I know where my money was going and what good it was doing for the cause?

T: One of our principles is full transparency. So, we do publish reports on, ya know, who we are, how much we raise, where it goes. And that's available on a local level as well as on a national level, so anytime anybody asks, that's available. We also put it in our annual report.

Me: I saw some links on your website...is it put on there, or does someone need to call in a say, "hey I'd like a copy of this?"

T: Our annual report every year is folded into our newsletter, because our annual report we wanna send it out to all our local constituents, and so that's also available online, the newsletter is. The um, guidestar.com will have your tax return on there your 990 form, and that's available for any chapter and the national office. What else? There's all kinds of, ya know, oversight reports out there. We have um, the national puts together a pamphlet every year, every two years...every year or two and it says ya know just the facts and it includes in there the financial breakdown. So it's out there if you know where to look, but if you don't know where to look you can certainly call and ask cuz...I can either give it to them or I can redirect them.

Me: There's also a website, I don't know if you've heard of it, it's called give.org.

T: Yes. :D

Me: Yeah, I looked you guys up on that, so you scored very well...LOL.

T: Um, well for a long time, I don't know if we still are, but we were the only MS organization that met or exceeded the standards of all of the oversight groups that evaluate nonprofits. So, we were the only MS organization there that met all those...so that was pretty powerful.

Me: Yeah, that is. Um, How are donations and your budget and membership affected by, um, national and international disasters like Hurricane Katrina? When so many people are giving their money towards this immediate relief that at the end of the year, they're like, I just don't have as much money to give to this organization as I normally would.

T: I will give you a couple of examples. Um, again I would say that most people who give to us have a personal connection and that does not change. People are always going to give to us if they have a personal connection, they may have less to give but they're not going to stop giving. Um, Katrina hit us hard, our LA chapter was wiped out and we did a special plea and we were able to raise funds for that so people who still wanted to give to Katrina could help give to

Katrina and MS. Um, that's one example. But it does impact us in the sense that when our LA chapter was lost, um not only was it a problem that we couldn't find all of our clients, um, and our staff...but we uh we couldn't have our events that were there to raise money for our chapter. Ya know the bike, the bike event that we had out there every year out there needed to be done in ya know like Georgia, and like Alabama hosted it for us. So the people who still wanted to participate and raise money in the bike ride, just did it in Georgia and Alabama. So I mean there are accommodations that need to be made. Another situation that was in the news several months ago, one of our very top donor/volunteer families in Connecticut was involved in a home invasion. And the mother who had MS, and her two daughters were brutally killed, um the father survived the attack but he was attacked as well. And so, in that case, ya know the community came together and raised money in a special fund for the MS Society under the father's wishes. Uh, and so the money's that were lost, what his being one of our top fundraising families, ya know the special fund came up in special memory of these individuals. Ya know, there are different ways that disaster has affected us...but um, people still open their hearts to give.

Me: Did he organize that, or was that the community trying to reach out and support him and his wife?

T: Both. Um, ya know the community and the community at large, not just CT but all of us around the country were touched by that. I mean that, I think, this is just me speaking not the Society speaking, but I mean that's one of ya know a lot of people's biggest fears is some random attack in your home. This was completely random. And uh, these people just happened to pick this house: prominent family in a very busioux neighborhood. Um, and it was it received national attention, it was on the national news it ya know was on Comcast, CNN homepage. So when you, anybody who around the country pulled that up or around the world saw that...um, and so when there's a situation like that, or when there's a situation like Sept 11, or there's a situation like Katrina, or the Tsunami...obviously they wanna do something and they don't know what to do so they open their wallets. So people who are wanting to make a donation, wanting to give somehow to help this family, they didn't need the money, so the father obviously just set up a fund because in honor of his wife, who was living with the disease and his daughter who was a top fundraiser for that chapter. He said, well let's set up this fund so people can express their grief in this way.

Me: It seems to be a trend that, um, breast cancer and um other non-for-profit organizations are selling items in order to raise money, like I saw on your website that you're doing the new thing with Crocs. And um, well my first question was...did the Crocs company approach you with that, or was that something you set up with them?

T: There are...it's done different ways. Um, on our local website you might see that there are a number of things people sell for MS. And um a lot of those are done because somebody, ya know we call a lot of these things "third-party events" and that's if somebody's raising money on our behalf we don't really have to do anything it doesn't take any staff time really to manage it, it's volunteer driven. And so there are a lot of people out there that'll say, "Oh I make jewelry, that's my thing. And I wanna make jewelry, sell it, and raise money for you." We have another man who has started a company just to raise money for MS. My understanding about Crocs, cuz

that's a national initiative...Crocs was getting involved in this Crocs Cares program that identified a couple of charities that they wanted to look at, I think the American Cancer Society might be the other one. And so...there was a connection that they made with the national office. Um...it's not something that we spend a lot of time to go out and say, we wanna try to see who we can partner with, but if there's a connection, if there's someone at Crocs who's high level and has MS obviously we'll have those conversations.

Me: Do you know what the breakdown of the percentage of that is? What money goes towards actually making the product, what money goes towards Crocs themselves, and what money goes towards you?

T: I don't have any idea how much money Crocs spends on their product, but the breakdown is that \$2 of every pair that they sell of this particular MS Society goes to the MS Society. But I don't have any idea what their overhead is...

Me: That's okay, lol.

T: I mean it doesn't seem like there's a lot of cost in the materials for Crocs, but I don't know what production costs and everything are.

Me: UM, how did the Society begin the MS Walk and the bike riding um, fundraisers? Where do those come from?

T: Ya know, those have been going on for 20-25 years so that's a little bit before my time, I wasn't involved with that, but ya know nonprofits generally people started doing walks to raise money and they were very easy, grass-roots types of things that were managed from the grass-roots up and powerful fundraisers. I mean, look at race for the cure, they raise an enormous amount of money every year and have enormous amount of people attend. So, I don't now how...I know the MS Society proly did that with the walk, they proly just saw the idea from somebody else. But we were one of the first to have any kind of a bike ride...so um, I don't really know how that came about.

Me: It just, it intrigued me because it seemed like..."we're going to ride bikes for people who can't ride bikes themselves." Ya know?

T: Well, I mean I think that's, yeah there're a lot of people that can ride bikes with MS, ya know 85% of people with MS never even will require mobility aid. So, I mean I, I think there's a general misconception about that and I really was trying to educate people here...I mean we have people who have MS who use recumbent bikes that just require their hands, just the little three wheeler trikes, recumbent bike. And so I really feel like we need to...and I guess, I mean this is a good point, I mean your mother has MS so this is a good statement to me, is we need to do more to educate people that yes people with MS can participate in this or their family members can. Ya know? Uh, a bike ride is definitely a little bit more exciting than a walk, and it's more strenuous...

Me: I've seen articles too where, um, someone has gotten involved in the MS Society because they liked to bike, and they thought biking for a good cause would be fun. And so, through that they really have no connection really to MS, but they do have a connection to bike riding and that has gotten people involved.

T: Yeah, definitely. The, I would say the cycling event is probably the one that has the more non-MS Society constituents than any other event, for that very reason. Because cycling is big in a lot of places. The MS 150 is a great ride; it's a 2-day, 150 mile challenging ride and um, I mean we obviously have other options as well if people want to do less than 150 mi. But it's not just something the general public just jumps at, it's the cycling community.

Me: Would you happen to have an idea of...when setting up these events, how much of the money that's raised goes back into setting up the event, rather than going towards where the money...

T: You mean cost benefit analysis?

Me: Yeah...

T: I would say, I don't have an exact percentage for each event. That's always something we're trying to do is do individual cost benefit analysis so we can see if it's worthwhile for us to have an event. I can tell you, special events...very low overhead. The actual cost...aside from staff time, the actual cost of the materials and everything putting a walk or bike ride together is minimal. Most of those logistics materials we get donated...if you have something like one of women's luncheons, our dinner champions...the overhead is much higher because you're paying for a nice meal, you're paying for a facility. And then the return on that, ya know, hopefully makes that worth your while, lol. But as a national office, and as a chapter, our certification requirement is that we have to be 25% or under in our management and fundraiser expense. And that's a national industry, nonprofit industry standard, and last year we were 24.6 I think...so we always try to hit under 25%. And basically all that means is that 24.6 cents of every dollar goes towards fundraising and admin fees.

Me: Um, I was reading a little about the Action Alert Network and all of the policies they're working for...do you know what are some of the current public policies they're advocating for right now?

T: Well, the three...We have some top priorities for 2008, um, public policy conference we have every year and we have an MS Day on the Hill where we go and people from every chapter volunteer to staff, go and advocate for MS issues. Last year, um ya know I could tell you every year we're advocating for increased NIH funding, National Institute of Health funding for MS. We also, ya know the initiatives change a little every year, but last year we focused on, um, ...there's a Medicare restriction for uh the use of wheelchairs and scooters, and basically what it says, and it's a 25 or 30 year old restriction, it basically says that any, uh, how can I say this? And word it properly...any Medicare funding for a wheelchair or scooter, you need to have it, you need to be required to use it in your home. So, Medicare will only pay for wheelchair or scooter for somebody who basically needs it all the time and needs it within the home. Now our



situation with MS is such that, there...fatigue is the number one system that people have, and so they may not need it within their home, they may be able to get by with a cane or walker or walking along the wall in their home, but yet if they're going shopping, or they're going to work and it requires them parking and walking into a building or even getting into the building and walking a considerable amount of time till they get to their desk or something...it's very restrictive and that can be quite debilitating to people because they're...the fatigue levels are so high. And so, a lot of our clients use the wheelchair or scooter outside the home, but they're not able to get funding for it from Medicare because of that restriction. So we have for a long time tried to get that restriction lifted; there's a lot of opposition to that though because there's a high level of fraud in the Medicare program. And people who, ya know, use it for ya know, they misuse it...um, other issues we've advocated for are accessibility and housing. We have advocated for increased drug coverage, ya know the Medicare coverage of some of the MS treatments is something that we've worked on for a long time. Those kinds of things.

Me: Ya, my mom when she first got her wheelchair was really just for outside of the home. Um, for going long distances and things like that.

T: Well a lot of our clients don't even have accessible home, so they really can't have a wheelchair or scooter in their home, cuz they can't manipulate it within the home. But they can do a walker or cane or something. There's a misconception about ya know the general public who they see somebody in a wheelchair or scooter and they think they can't walk at all and with MS that's not always the case. But, ya know people then look at them and are like, well why are you in a scooter if you can walk, but they don't understand the debilitating fatigue that comes along with the disease. It's a misconception we fight.

Me: Um...with so much money going towards research, what information is being put out there so that donors know that advancements are being made and that things are I guess getting closer to a cure?

T: Well, there's uh, there's always a marketing and PR push, so when any kind of research finding comes out we do national media. Um, locally we do our research email alerts so we have a group of several hundred people who just want email alerts on research. So anytime something new comes out we send it out to them. Um, we have an extensive amount of information on our national website, dedicated to research and our specific research campaigns and updates on that. We have, um quarterly newsletters that comes out with all their research updates. For our specific donors at certain levels, especially if they're interested in just funding research, there are special newsletters and special mailings that go out to them. It's definitely everywhere...

Me: Uhuh, you have a whole research link on your website that I saw.

T: Yeah, it's huge...and within that several sublinks.

Me: It was a lot of information to take in, lol. Well, those were all my questions. Was there anything else you wanted to share that I didn't ask?

T: I would be happy to give you any of our publications that you might want.

Me: That would be fabulous.

T: We just had our new newsletter that just came out, so I have a copy of that I can give you.

Me: If by some chance when I'm writing my paper I have one or two extra questions, can I email those to you?

T: Absolutely, you can email me, and give me a time frame of when you need it. Lol, I think I'm not traveling as much in the next few weeks...cuz I was out most of the last two weeks, and if there's any information that your mother would like to have we have a whole closet full of stuff.

Me: Okay, I will let her know. Thank you for your time.

T: Thank you, and good luck with your project.

**Appendix B:**

**Letter of invitation to contribute to the NMSS and “Guide to Giving”**

Dear \_\_\_\_\_

The end has come at last! I have finished all my course requirements at Ball State University and am finishing the last requirement for my degree. This means that I am working on a project all my own that will act as a capstone to all my studies at this university: my Honors Thesis. This requirement for my Honors diploma gives me the opportunity to do in-depth research on a topic that is meaningful or important to me, and I have chosen a topic dear to my heart: Multiple Sclerosis.

More accurately, my research project is focused on charity foundations and nonprofit organizations that raise money to improve the lives of those who live with MS. This money can go to anything from researching for a cure to aiding families who are struggling financially. The goal of my thesis is three fold. First, I learned more about Multiple Sclerosis and the knowledge that research has uncovered about this disease. Second, I sought to understand the needs of those affected by MS and see where these are, and are not, being met by charities, specifically the National Multiple Sclerosis Society. Finally, I want to make a contribution to—and encourage others’ contributions to the NMSS—so that I am not only writing about doing good, but also participating in the organization’s important work.

This is where you come in! I have set up a memorial fund through the National Multiple Sclerosis Society whereby those who are interested in supporting my project, and the NMSS, can do so. This fund is dedicated to my late grandmother, Winifred Lorraine George, who was diagnosed with MS in 1960 and died in 1974. She gave birth to my mother, Carolyn Sue Metz,

in 1951, who was also diagnosed with MS in 1982. This disease has greatly affected my family, and as you are friend or family, it has affected you as well. This makes it an important and personal issue to all of us.

With this letter you have received a summary sheet of my project and a “Guide to Giving” so that you are informed and aware of how your donation would be put to use, should you choose to make one. I hope that the factors identified in the enclosed “guide” will help to aid you with your giving to other places in the future as well. Not only should the guide give you an idea of what good the NMSS does with your money, but it will raise issues for you to consider when making future donations.

If you are interested in helping me with the third goal of my project, please go to [www.nationalmssociety.org/donate](http://www.nationalmssociety.org/donate) and click on “Donate to an existing fund.” Then type “Winifred” in the search box, click the “Find a Fund” button, and select the Winifred Memorial Fund. Once at the Memorial Fund site, click the “Donate” link on the right and follow the instructions to give your donation. If you would prefer to donate through the mail, please make a check out to Winifred Memorial Fund and send it to:

**National MS Society**  
**PO Box 4527**  
**New York, NY 10163**

If you have any questions or concerns, my information is below, feel free to contact me.  
Thank you for taking the time to help fight MS and to support those who live with it!

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## Guide to Giving

**Cause:** Multiple Sclerosis is an autoimmune disease that affects approximately 2.5 people worldwide. It causes the body's immune system to attack the protective coating surrounding the nerves in the Central Nervous System, called myelin. This results in debilitating fatigue and, often, loss of mobility.

### **4 ways to determine YOU are doing the most "good" with your donations:**

1. Determine the worth of the project.
  - a. Is there genuine need?
  - b. Is the organization you give to going to accomplish more per dollar than another?
2. Determine a just and fair distribution of aid.
  - a. Is the organization you give to following their mission statement?
  - b. Are the recipients of aid being given what is deserved or due to them?
3. Determine that the organization has set priorities.
  - a. Does it have a clear mission statement?
  - b. Does it have clear goals in order to achieve that mission statement?
4. Determine that the organization has an accurate way of measuring the efficiency and effectiveness of the work it does.
  - a. How does the organization itself ensure it is in touch with the needs of those it is trying to help?
  - b. Does it provide proof to its donors that the money it received has been put to good use?

The website "Give.org" created by the Better Business Bureau (BBB) "Wise Giving Alliance" is an excellent on-line resource for assessing these criteria.

### **An EXAMPLE:**

#### **The National Multiple Sclerosis Society**

1. Determine the worth of the project.
  - a. Roughly 400,000 diagnosed cases in the U.S.
  - b. The NMSS is the leading philanthropic organization in America addressing the needs of those with Multiple Sclerosis.
2. Determine just and fair distribution of aid.
  - a. The NMSS provides services from financial counseling and aid, to coordinating worldwide research.
  - b. These services attempt to achieve the broad mission statement to "End the devastating effects of MS"

3. Determine that the organization has set priorities.

a. The mission statement has been further detailed with 5 main goals that came out in 2005:

- We are a driving force of MS research, relentlessly pursuing prevention, treatment, and cure.
- We address the challenges of each person whose life is affected by MS.
- We mobilize the talents and resources of the millions of people who want to do something about MS.
- We are activists.
- We will raise a total of \$1.25B by the end of 2010 to be used in the fight against multiple sclerosis.

\*2006 publication of the NMSS

b. State chapters of the NMSS are given flexibility—and assume responsibility—to adapt their activities to their specific clientele.

4. Determine that the organization has an accurate way of measuring the efficiency and effectiveness of the work it does.

a. Needs-based assessments are done every 3-5 years.

b. The NMSS has an attitude of "full transparency" and their financial records can be found via telephone or the website "Give.org."

Please keep these questions in mind when considering making further donations to any cause. Stash this guide by your phone and ask these questions of the organizations that desire your contributions. An organization with nothing to hide will be more than willing to answer them.

Remember: Give where your heart leads you!

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